

Meeting the challenges of dementia in prisons

Roundtable discussion briefing paper



National Dementia Action Alliance

INTRODUCTION TO CAMPAIGN

This briefing paper has been produced to launch the National Dementia Action Alliance's (NDAA) campaign to improve care and support for people affected by dementia from seldom heard groups.

ABOUT THE NDAA

The NDAA is a network of organisations who commit to taking action on dementia. Through our work, we aim to improve health and social outcomes for people affected by dementia. The NDAA was set up in 2011 following the government's National Dementia Strategy of England, to bring together key organisations to gain their commitments to achieving the outcomes outlined in the strategy. Since then it has gone from strength to strength and we now have over 150 members.

The role of the NDAA is to bring together our members to connect, share best practice and take action on dementia. We also campaign on key issues affecting people with dementia and their carers. Past campaigns we have organised have improved dementia care within hospital settings, reduced anti-psychotic drug prescriptions and improved support for carers.

Our 2017 campaign will focus on improving care and support for people affected by dementia who come from seldom heard groups. The campaign has three primary objectives:

1. Raise awareness of the challenges faced by people with dementia from seldom heard groups
2. Influence system wide change
3. Bring about organisational change

As part of the campaign we will hold a series of roundtables, each focusing on a specific seldom heard group. Through the roundtables we will explore areas where progress is needed and where the NDAA, through the influence of its members, can affect wider change.

We will run roundtables focused on dementia in the following groups:

- Prisons
- Lesbian Gay Bisexual & transgender
- Learning disabilities

DEMENTIA AND PRISONS

Overview of main issues

This paper will seek to outline some of the main challenges affecting people with dementia in prisons. We hope to identify a specific area where change is needed and then through the roundtable explore a desired outcome and way of achieving this.

Dementia is a growing problem within prisons. Prisoners over the age of 60 are the fastest growing age group in prisons, with the latest figure standing at 10,000. This number is set to increase unless there are major changes in sentencing trends. There is currently no national plan for older prisoners, but action is needed. There is still limited understanding of the needs of older prisoners in England and Wales and this should be addressed through the NDAA's campaign.

As the number of older prisoners rises, so too will the prevalence of dementia. People with dementia in prisons will face a number of challenges just by being in this environment, and many of these will be exacerbated by cuts to the prison service. Keeping people in prisons can be costly, so it is important to ensure that they are dealt with appropriately, to avoid unnecessarily long sentences. Good practice does exist, but there are not enough opportunities to share this across prisons in England.

A good starting point for this discussion is to understand that many of the challenges faced by people with dementia in prison settings are the same faced by those living in the community, however due to the uniqueness of a prison setting they are more acute.

These issues are wide reaching and span right the way across the dementia journey - before the point of diagnosis through to end of life. Simply receiving a diagnosis can be challenging in a prison setting; some of the specific challenges are outlined in more detail below.

Receiving a diagnosis

Prison staff are expected to understand a number of health conditions and forms of disability, and to respond appropriately under massive pressure caused by budget and staffing cuts. However, many lack the training required to spot the signs of dementia and to make the relevant referrals. This means that prisoners' dementia can go undiagnosed, leaving them without support in an environment that can be hostile to their needs. Whilst most prisons are required to conduct health screenings, they do not typically look for issues related to aging or cognitive decline. This means that a condition such as dementia could easily get missed.

Responsibility and accountability for delivering care

If a prisoner does receive a diagnosis, the support they receive can be variable depending on the geographic location of their prison. The Care Act states that local authorities in England are responsible for assessment and meeting eligible care and support needs for prisoners located in their area. As part of the Act they should be treated as though they are a resident of that local authority. However despite this being enshrined in law, there is still some uncertainty as to who exactly has responsibility for meeting the social care needs of prisoners. This can result in hospital admissions and in some cases even deaths, both of which can be avoided. Examples have existed of prisoners' treatment being stopped upon entering prison, records not being passed on or medications not given. If this care is not comparable to those in the community, it raises questions as to whether the human rights of prisoners are being neglected. A prisoner should not lose these rights because they are incarcerated.

Routines which deskill and disempower

The regimented and routine nature of prison life can be very problematic for people with dementia for a number of reasons. This lifestyle can take away the individual's ability to think independently, which can de-skill them to even basic tasks and activities. This can be especially problematic when they are released and find themselves unable to look after themselves.

Many prisoners can struggle with the standardised regimes and timetables they are expected to adhere to, which can result in them missing out on important activities - for example exercise if they can't reach the gym in time. Older prisoners can be neglected due to them typically being less trouble than younger inmates, which can again lead to them becoming socially isolated.

Confusing environments

The physical environment of a prison can bring a whole host of challenges to a person with dementia if their needs are not properly understood. Some people, such as the Prison Alliance, argue that the prison environment is in fact completely unsuitable for older prisoners, particularly if they pose no threat to the public or to the other inmates, and if their health and social care needs could be more effectively met in the community.

Some of this also depends on the age of the prison estate. The Ministry of Justice have claimed that newer estates are better suited to meet the needs of older prisoners, whereas older prisons can cause numerous problems. An example of these issues can include overcrowding, lack of accessibility such as ramps, and different areas of the prisons looking

the same. All of this can lead to prisoners with dementia retreating to their cells and spending more time alone, which studies show can lead to cognitive decline.

The right training

Looking after older people, particularly those with complex care needs requires training and skills, which can sometimes be lacking amongst prison staff. Without the right kind of support and understanding of how dementia can affect an individual's behaviour, prisoners can spend longer in prison than necessary. If this is reversed and prisoners with dementia are better understood and supported it may lead to them being released into the community.

Dementia and human rights

The issue of human rights is particularly pertinent when considering prisoners with dementia. Their dementia and the environment can impact on their behaviour, which in turn could lead to cognitive decline, resulting in an extended sentence. In addition to this, the aims of incarceration, whether punitive or rehabilitative, could be lost on a person with dementia so this should be considered when sentencing.

Conclusion

In conclusion, clearly the issue of dementia within the prison setting is very complex and given the current backdrop it is likely to get worse. As the number of older prisoners increase, so do the chances of more prisoners with dementia, who need to be supported by rights, but also to ensure prisons aren't incurring additional financial strain. Prisons are woefully underprepared to deal with such challenges. Environments are unsuitable and staff knowledge of the condition is severely lacking. As with many public services, budgets are being cut which means interventions are much more difficult to implement.

In spite of the somewhat gloomy outlook, there are things that can be done to improve circumstances for both the prison system and the prisoners. Good practice does exist and it isn't always about pumping in more funding. It is important, through this campaign, that we highlight the specific things that can be done, whilst at the same time pushing for the wider changes that need to be made.